BEFORE THE OFFICE OF ADMINISTRATIVE HEARINGS STATE OF CALIFORNIA

In the Matter of:		
HANNAH G.,		
Claimant,	0.44.6	
Vs.	OAH Case No. L 2006020675	
HARBOR REGIONAL CENTER,		
Service Agency or Respondent.		

DECISION

Vincent Nafarrete, Administrative Law Judge of the Office of Administrative Hearings, heard this matter in Torrance on January 22- 26, 2007, and March 26 – 27, 2007. Claimant Hannah G. was represented by Thomas E. Beltran, Attorney at Law. Claimant's mother was present throughout the hearing. Respondent Harbor Regional Center (hereinafter also Service Agency or regional center) was represented by Mona Z. Hanna, Attorney at Law.

On February 28, 2006, this matter was consolidated with four other fair hearing requests filed by claimant which had been assigned OAH Case Nos. L-2006010604, L-2006010631, L-2006020717, and L-2006020732. All five fair hearing requests were consolidated under the present matter, OAH Case No. L-2006020675.

This matter was scheduled for a one-day continued hearing on September 21, 2006. Respondent's counsel came prepared to participate in a fair hearing in which the issues were limited to whether the regional center should reimburse claimant for supplemental pay to caregivers and commissions paid to an employment agency. Claimant's counsel, on the other hand, anticipated that the fair hearing would also include other issues, including issues regarding feeding and the appropriate level of care. Respondent's counsel disagreed, contending that those additional issues had been previously resolved, in part, by the discussions between the regional center and claimant's mother. Thereupon, claimant's counsel requested that those earlier resolutions be rescinded so that the issues for the fair hearing could be expanded. After a discussion, the parties jointly agreed to continue the fair hearing,

claimant waived the time requirements for conducting a fair hearing, and claimant was directed to file an amended fair hearing request.

On October 19, 2006, a telephonic conference was held with the parties and the continued hearing was scheduled for January 22 – 26, 2007. Claimant was also directed to file an amended fair hearing request setting forth issues for the hearing. On or about October 25, 2006, claimant's counsel filed an amended fair hearing request, which included a table of extra costs paid by claimant for caregiver services (Table A).

On December 14 and 19, 2006, Administrative Law Judge David Rosenman conducted a prehearing conference with counsel for the parties and issued a Prehearing Conference Order thereafter. Based on the amended fair hearing request and discussion with the parties, ALJ Rosenman determined that the issues to be determined at the fair hearing were as follows: (1) whether claimant should be reimbursed for psychotherapy for family members and, if so, at what rate of reimbursement; (2) whether claimant should be reimbursed for costs of caregiver services from 2002 to the present as set forth in Table A of the amended fair hearing request; (3) whether the regional center should be ordered to discontinue issuing Internal Revenue Service Form 1099 to claimant's mother for funds paid to her as reimbursement of caregiver costs; (4) the appropriate level of care for claimant under the Lanterman Act; (5) whether the regional center should be ordered to establish compensation packages, including pay raises, sick pay, paid holidays, and vacation pay, for claimant's caregivers; and (6) whether claimant should be reimbursed for her costs of obtaining respite workers when existing caregivers were unable to work. Under the Prehearing Conference Order, the Service Agency was reserved the right to challenge the appropriateness of any of these issues for a fair hearing.

Prior to or at the continued hearing on January 22, 2007, claimant filed the following motions or requests: Request for Official Notice of Prior Administrative Decisions and Motion in Limine that Certain Findings from Prior Proceedings be given Collateral Estoppel Effect. Respondent filed, in part, the following: Opposition to Claimant's Motion in Limine for Collateral Estoppel, Motion in Limine to Dismiss, and an Opening Brief. Respondent argued that certain issues determined at the prehearing conference were not appropriate for the fair hearing. In addition, both parties submitted witness and exhibit lists.

At the commencement of the hearing on January 22, 2007, the Administrative Law Judge took official notice of the prior decisions of the Office of Administrative Hearings in the matters of Hannah G. v. Harbor Regional Center in Case No. L-200009073 (November 13, 2000), Case No. L-2001120515 (May 30, 2002), Case No. L-2002090357 (December 13, 2002), and Case No. L-2004010211 (May 18, 2005). The Administrative Law Judge noted that these prior decisions were final administrative decisions under Welfare and Institutions Code section 4712.5, subdivision (b)(2), and ruled that these decisions would be given collateral estoppel

effect in the instant fair hearing with respect to the issues litigated and for the time periods determined in those prior decisions.

Based on rulings on the parties' requests and motions, claimant's amended fair hearing request and Table A, the prehearing conference order, and prior decisions, the Administrative Law Judge determined that the issues to be determined at the fair hearing were as follows:

- (1) Shall the Service Agency reimburse claimant for psychotherapy provided to family members by Melvin Lewin, Ph.D., and Randall Hulbert, M.D., and, if so, at what rate of reimbursement?
- (2) Shall the Service Agency reimburse claimant, as set forth in Table A of claimant's amended fair hearing request, for payments made to caregiver Vivian Mendez for extra pay, vacation pay, and holiday pay from December 2002 through May 2005; for payments made to caregiver Delfina Villa for vacation pay and holiday pay from December 2002 through May 2005; and for payments made to caregiver Sandra Dryer for extra pay from May 2005 through to the present?
- (3) Shall the Service Agency rescind restrictions for the feeding and care of claimant (i.e., feeding by a licensed vocational nurse or by gastrointestinal tube) without requiring the parents to sign a waiver of liability of potential claims that may arise from oral feeding or otherwise? and
- (4) What is the appropriate level of care for claimant insofar that claimant requires various services for daily living and therapies and her caregivers or respite workers have been trained to perform these services but do not necessarily possess the training or experience of nurses or therapists?

With regard to the other issues set forth in the prehearing conference order, the Administrative Law Judge determined that jurisdiction did not exist under the Lanterman Act to consider the accounting and tax issue whether the Service Agency should discontinue issuing IRS Form 1099 for miscellaneous income to claimant's mother. The Administrative Law Judge further ruled that the issues whether the Service Agency should establish compensation packages for claimant's caregivers or reimburse claimant for costs for obtaining respite workers, including payments to an employment agency, were more properly the subject of the collaborative individual program planning process with prior service requests made to the Service Agency, as has been suggested in prior decisions, rather than a fair hearing.

The fair hearing commenced on January 22, 2007, and, after five days of hearing, was rescheduled for another five days beginning March 26, 2007. For its case-in-chief, respondent Service Agency called the following witnesses: Dolores Burlison, Director of Children's Services; Sri Moedjono, M.D., medical consultant

for the regional center; Patricia Zalenski, R.N., nursing consultant for the regional center; Paul Quiroz, director of Cambrian Home Care; and Kathleen Richards, program manager of the regional center. For her case-in-chief, claimant called the following two witnesses: claimant's mother and claimant's pediatrician Gary Donnell Anderson, M.D. Exhibits were marked and admitted into evidence.

Before the start of the hearing on March 27, 2007, and during his case-in-chief, claimant's counsel announced that claimant no longer wanted reimbursement of extra pay or benefits paid to caregivers. Based on that representation, counsel for both parties requested a recess in the proceedings to discuss settlement. After the recess, both parties represented that they had settled all of the issues except for the issue regarding reimbursement for family or private psychotherapy. Thereafter, claimant's mother affirmed under oath that she and her attorney had reached a settlement agreement with the regional center that was acceptable to her. Claimant then presented further oral and documentary evidence on her request for reimbursement for psychotherapy sessions provided by Dr. Lewin. Claimant indicated that she was withdrawing a reimbursement claim for services provided by Dr. Hulbert and presented no evidence on that claim. The parties then agreed that the fair hearing may be concluded. The terms of the settlement agreement, however, were not placed on the record.

On conclusion of the evidentiary hearing on March 27, 2007, the record was held open for claimant's counsel to file an additional invoice for psychotherapy. On April 6, 2007, complainant's counsel filed the invoice, which was marked and admitted into evidence as Exhibit I-4.

On April 19, 2007, the Administrative Law Judge issued a Post-Hearing Order (Exh. J), directing the parties to submit documentation that they had reached a settlement on the issues discussed on the last day of hearing. On or about April 27, 2007, the Administrative Law granted the parties' request for a one-week extension to file their settlement document. The request for extension was marked as Exhibit K. On May 4, 2007, respondent's counsel filed the letter agreement of the parties, which was then marked as Exhibit AAAA and admitted into evidence.

Oral and documentary evidence having been received, the Administrative Law Judge submitted this matter for decision on May 4, 2007, and finds as follows:

ISSUE

The sole issue presented for decision is whether claimant should receive reimbursement from the Service Agency for private psychotherapy or counseling provided to family members by Melvyn M. Lewin, Ph.D.

FACTUAL FINDINGS

- 1. Claimant is a ten-year-old girl who was diagnosed with Canavan's disease at six and one-half months of age. Canavan's disease is a rare, degenerative disorder caused by changes in or from a brain enzyme and results in developmental and neurological delays as well as physical problems, including seizures and/or feeding difficulties. It is a progressive disorder and persons afflicted by Canavan's disease generally have a shortened lifespan. In claimant's case, claimant is blind, unable to move or walk, unable to sit up without help, and cannot feed or care for herself. While she can communicate in some manner, claimant is unable to talk. As such, claimant requires around-the-clock, total care from a parent and/or caregiver for all of her daily living needs.
- 2. Due to her disabilities and developmental delays, claimant has been a client of the Harbor Regional Center from a very young age. From the regional center, claimant receives each month approximately 372 hours of respite or caregiver services. In the past, she has also received weekly physical therapy, speech therapy, and occupational therapy funded by the regional center. Claimant also receives 248 hours monthly of In-Home Support Services (IHSS) from Los Angeles County and approximately 64 hours monthly, or 15 hours weekly, of assistance from a one-to-one aide while she attends school.
- Claimant lives with her parents and school-age brothers in the family home in the South Bay area of Los Angeles County. Her father has a full-time job and her mother works part-time as a nutritionist for a hospital oncology unit. Claimant attends an early intervention school in the Palos Verdes Peninsula Unified School District for three hours each school day. With the respite care hours provided by the Service Agency, IHSS hours, and one-to-one school aide, claimant's mother has been able to organize and arrange for 24-hour individual care for her daughter at home and at school. For several years now, the mother has had one steadily employed caregiver, Vivian Mendez (hereinafter also Mendez), who cares for claimant for approximately 30 to 40 hours per week at home and is also paid to act as an aide for claimant while she is at school. In addition, the mother has had other caregivers who have worked in her home for different periods of time. Because claimant requires care for all of her needs, is immobile, and has a rigorous exercise and feeding regimen designed by her mother, caregivers have difficulty in caring for claimant and the mother has found that it is difficult to retain caregivers for any long or consistent periods of time.
- 4. To have caregivers come to the house to care for her daughter, the mother is generally required under the practices and policies of the Service Agency to contact the authorized respite care provider, Cambrian HomeCare (Cambrian), which hires and employs respite caregivers for clients in their homes. However, more often than not, claimant's mother has instead chosen to use a private employment agency to find caregivers, hire them on a trial basis to train them, and then refer them to

Cambrian to be employed and paid under the respite care contract with the Service Agency. Except for caregiver Mendez, Cambrian pays claimant's caregivers approximately \$12.50 per hour, which is a higher pay rate negotiated between Cambrian and the Service Agency, but does not provide the caregivers with vacation, holiday, or sick pay. Due to the nature of the work, Cambrian has a high turnover in caregivers, fifty percent of whom leave within six months. For different reasons then, claimant's mother continues to have difficulty in filling work shifts for the care of her daughter with Cambrian workers and prefers to find her own caregivers without first seeking help from Cambrian.

- In prior decisions, claimant's mother has prevailed on fair hearing 5. requests and ostensibly obtained confirmation that the way she obtained, retained, and paid caregivers was understandable, due to the intense and constant needs of her daughter and the inability of Cambrian to consistently hire caregivers, although not in keeping with the service coordination and request process under the Lanterman Act. In the Decision in Case No. L-2002090357, dated December 12, 2002, the Service Agency was ordered to reimburse claimant in the sum of \$28,611.80 for extra pay, vacation pay, and holiday pay that claimant's mother made to caregivers through October 2002. In the Decision in Case No. L-2004040211, dated May 18, 2005, the Service Agency was ordered to prospectively provide funding such that claimant's primary caregiver, Vivian Mendez, would receive weekly pay of \$650 for a 40-hour workweek, two weeks of annual paid vacation, and holiday pay, and that another long-term caregiver would receive two weeks of annual paid vacation and holiday pay. As a result of this decision, caregiver Mendez has been paid at a higher salary than other caregivers from Cambrian. Claimant's mother was able to establish that she had difficulty in finding and retaining qualified, long-term caregivers at the salary paid by Cambrian, that she had to use and pay an employment agency to find caregivers, and that she has had to pay extra compensation and/or vacation and holiday pay to long-term caregivers in order to retain them. The mother also demonstrated that the in-home care and exercise program that she has been providing to her daughter is not only beneficial and has prevented further injuries or physical disabilities but also is arduous and time-consuming for the parents and trained caregivers to implement.
- 6. (A) On a daily basis, claimant awakens in the morning after sleeping in her bedroom with a caregiver. While claimant is asleep, the caregiver must change her body position for comfort, move her head to prevent gagging or choking on her own saliva, change her diaper, and comfort her so that she does not wake up screaming and she and other family members can sleep through the night. Before breakfast, a caregiver and her mother will compress her joints, have her sit on a therapy ball for head and neck strengthening, have her perform oral motion exercises, and make her stand in her standing device for 10 to 15 minutes. Claimant requires 25 to 45 minutes to be fed breakfast and she will then perform arm and floor exercises for 30 minutes. On school days, claimant will be dressed and driven to school where

she will be assisted by her caregiver Mendez, who is paid to be an aide by the school, for approximately three hours.

- (B) After noon, claimant returns home for lunch which takes 30 to 60 minutes due to her difficulties in oral feeding. Before lunch, her mother and caregiver will have claimant undertake further oral motion and standing exercises. After lunch, she will stand for another 20 minutes to help her digest her food. Thereafter, claimant takes a nap for an hour or an hour and a half until about 3:30 or 4:00 p.m. A caregiver does not sleep with claimant during her nap but a caregiver or her mother is in the house. After her nap, claimant will receive a massage and perform physical therapy or stretching exercises for an hour. Before dinner, she will ride a special bike, stand in her stander, play with toys, stretch on the exercise ball, or play with her brothers outside or on the trampoline while being supervised by a caregiver or parent. Claimant usually eats dinner at about 6:00 p.m. and the meal takes one hour. After dinner, she will stand again for 15 to 20 minutes and then play or stroll in a walker around the neighborhood. At about 8:00 p.m., claimant is bathed and then performs additional exercises and stretches before going to bed. Claimant almost always has a caregiver in addition to a parent caring for her and supervising her activities during her day. To perform her various exercises and activities, she must be lifted and carried which is difficult for her caregivers and parents because she weighs over 30 pounds, her body is stiff and immobile, and she is sometimes resistant.
- (C) The daily exercise and stretching regimen provided to claimant in her home was designed and has been implemented by her mother based on her research on Canavan's disease. The oral motor exercises and techniques were started by an occupational therapist and feeding specialist provided to claimant by the Service Agency. In addition, the parents have taken claimant to Poland for treatment at a rehabilitation center for children with cerebral palsy and disabilities on approximately eight occasions.
- 7. (A) In the summer of 2005, the parents sent claimant to Poland for treatment for five weeks with caregiver Mendez, Mendez's sister, and Mendez's daughter. When she returned home in or about September 2005, claimant did not fare well with the new caregivers in the home or family members and began having more pronounced feeding or eating problems as well as related behavioral issues.
- (B) Claimant has had a problem with eating or feeding since she was a very young child. When she first became a client of the regional center, claimant had a feeding problem due to irritability. Later, the Service Agency provided claimant with occupational therapy so that she could learn oral motor skills. She also had difficulty eating solid foods, would bite her own tongue or lip, and had difficulty swallowing. In May 2004, the mother advised the regional center that claimant was fighting and screaming during her meals and she was afraid claimant would choke. In May 2005, the mother wrote again that claimant was suffering through dinner. In

September 2005, after returning home from Poland, claimant would not let anyone, except caregiver Mendez, touch her. She would scream, stopped vocalizing, and would bite her own mouth and tongue, resulting in open sores. Claimant was extremely irritable and resistant, especially during meals. Meals became very prolonged and stressful for the family due to claimant's irritability, incessant screaming, and refusal to eat. Claimant began losing weight.

- 8. On October 26, 2005, the mother wrote to the regional center service coordinator that the family was in a "crisis mode" because claimant was "so unhappy nearly all the time" and screamed during all meals. Claimant was refusing to eat or take her medications. On the prior Saturday, it took over two hours for the mother, her sister, and a neighbor to calm and feed claimant. The mother indicated that the feeding difficulties were very stressful for the family and getting progressively worse. The mother suggested services of a behaviorist might help.
- 9. (A) The next day, October 27, 2005, claimant's mother wrote to the service coordinator that there was an "impending disaster in [her] family" and that she feared for the physical and emotional safety of her family. The mother indicated that, three days earlier, she had to make an emergency visit with Melvyn M. Lewin, Ph.D., for immediate intervention. She stated that Dr. Lewin had been involved with her family for many years and he was someone that the family knew and trusted. Claimant's mother requested that the Service Agency provide funding for Dr. Lewin's services for the family and asked for reimbursement.
- (B) On November 3, 2005, the service coordinator acknowledged receipt of the requests of claimant' mother for services by Dr. Lewin and asked for more information regarding the type of services provided by him. The service coordinator also asked the mother for her consent to talk to claimant's physician regarding the recommendation for a behaviorist. Claimant's mother replied that she and her husband and son had all seen Dr. Lewin in the past two weeks for "emergency counseling for the stressful situation" in their family. She also asked for the services of a behaviorist to help deal with her daughter's feeding issues and indicated she would sign the consent for the Service Agency to talk to her daughter's physician about her feeding problems.
- 10. On November 7, 2005, the mother wrote to the service coordinator that her daughter's pediatric gastroenterologist had prescribed a feeding assessment by a feeding specialist. The mother indicated that she wanted to proceed as soon as possible on the feeding assessment since claimant had lost four pounds in the past two months.
- 11. On November 11, 2005, claimant's mother e-mailed to the service coordinator that it was "unbearable" to be at home with her daughter especially at mealtime and she just wanted to leave. Her sons closed their bedroom doors and could still hear their sister's screams and cries. The mother reported that claimant

and the family were suffering and the situation was worsening. She asked the regional center what she should do.

- 12. On November 15, 2005, claimant's mother sent to the Service Agency copies of invoices for therapy services provided by Dr. Lewin, added that she had to pay cash for the visits, and asked for reimbursement of her expenditure. She indicated that Dr. Lewin was helping her and her family to cope with "very difficult issues." Claimant's mother added that her daughter had a feeding evaluation scheduled with the occupational therapist and feeding specialist.
- 13. In November 2005, the Service Agency contracted with the occupational therapist and feeding specialist recommended by claimant's pediatric gastroenterologist to conduct an oral motor and feeding summary of claimant. The mother reported to the occupational therapist that claimant had been demonstrating resistance to feeding, extreme posturing, and loud prolonged crying. Two adults were needed to feed her, one as the primary feeder and the other as a food preparer and assistant. The mother also reported that her daughter bit her lower lip, cheek, and tongue during meals. The occupational therapist observed claimant being fed breakfast by her mother which took 75 minutes. Although she had not experienced any incidents of aspiration, the occupational therapist noted that claimant's diagnosis of dysphagia put her at high risk for aspiration. Due to her dysphagia and other related feeding concerns, the occupational therapist recommended ongoing feeding consultation with a therapist and swallowing intervention. The occupational therapist also found that claimant was capable of receiving meals from "skilled, trained and supervised" caregivers, needs a primary caregiver and another adult during mealtimes, and should be fed in a calm and quiet environment to reduce the risk of aspiration. The occupational therapist also expressed that claimant's "sudden, dramatic and continued weight loss" was of medical concern and needed to be addressed immediately.
- 14. On December 2, 2005, the mother e-mailed the service coordinator that claimant had been taken to the emergency room the night before because she was vomiting and had diahhrea. Claimant was found to be dehydrated and administered intravenous fluids. The mother expressed alarm that claimant was found to weigh only 26 pounds. She added that her daughter had lost eight pounds since the summer and needed help from the Service Agency for her feeding problems. The service coordinator replied that claimant's weight loss was a concern and suggested that she be assessed by her doctors. The mother replied that her daughter had already been evaluated by an OT and feeding specialist and needed immediate feeding and behavioral intervention to be provided by the Service Agency.
- 15. On December 7, 2005, the service coordinator asked claimant's mother to sign consent forms and releases for the Service Agency's medical consultant to be able to talk with claimant's pediatric gastroenterologist and neurologist. The mother signed the consent forms.

- 16. On December 27, 2005, claimant's mother wrote to the service coordinator that her daughter took two hours and 20 minutes to eat breakfast. She indicated that her daughter was very unhappy at mealtimes, for she would bite her lips, choke, twist and stiffen her body, and scream. During the day, claimant was "almost as miserable"; she whined, refused to do her exercises or play. Claimant was suffering and the family was at a loss what to do for her. The mother asked about feeding and behavioral therapy and whether the Service Agency was going to pay for psychotherapy with Dr. Lewin.
- 17. On December 27, 2005, the regional center's medical consultant, Dr. Sri Moedjono, became involved in claimant's case and noted that claimant had lost nine pounds over the last seven months. The medical consultant asked claimant's pediatrician about her weight loss, the risks of orally feeding her, and the need for further evaluation for gastrointestinal tube (G-tube) feeding. The pediatrician indicated he had not seen claimant for several weeks but was told by the mother that claimant was brought to the emergency room for dehydration. The pediatrician shared the same concerns about claimant's weight loss and oral feeding problems due to the progressive nature of her condition. The pediatrician further agreed that an evaluation for G-tube feeding may be appropriate if claimant was failing to thrive as indicated by weight loss and inability to eat.
- 18. On December 28, 2005, the service coordinator advised claimant's mother that the regional center was concerned about her daughter's feeding difficulties and wanted to ensure that she received the appropriate level of care. The service coordinator advised that the regional center's medical consultant had determined that oral feeding presented a serious risk to claimant due to choking, aspiration, and pneumonia and that claimant should be fed by a gastrointestinal tube or G-tube. The service coordinator further advised that the regional center had decided that, because of the serious health risk from oral feedings, claimant should not be fed orally by Cambrian caregivers and should receive care from licensed vocational nurses (LVNs). The LVNs were to care for claimant's needs and facilitate G-tube feedings but also would be allowed to feed claimant orally. Claimant's mother disagreed and was very upset with the regional center's decision about G-tube feedings and LVN care.
- 19. (A) On January 3, 2006, the Service Agency had a regional center nurse consultant Patricia Zalenski conduct a home visit to assess claimant due to recent weight and strength loss and feeding problems, including choking and screaming during meals, reported by the mother. The nurse consultant observed claimant after her afternoon nap and during dinner. Claimant required constant soothing and changes in position and activity to be calm; she frequently cried out or whined as if unhappy and irritated. She became upset soon after starting her exercise and stretching routine. When her diaper was changed by a caregiver, the nurse consultant saw that claimant's body, and especially her extremities, was unusually thin and she did not look healthy. Claimant weighed 28 pounds, which was five and

one-half pounds less than she weighed at her last nursing assessment in August 2004. At that last assessment, the nurse consultant had found that claimant was "very healthy" and had "no skilled nursing care needs." The nurse consultant found then that claimant's needs could be met by lay persons who were specifically trained to administer her exercise routine.

- (B) On January 3, 2006, nurse consultant Zalenski observed claimant during a 50-minute portion of her dinner. She was fed by her mother while a caregiver assisted by repositioning the child and reheating food. Claimant changed her sitting location while being fed. She twisted, squirmed, and cried throughout the meal. She required constant coaxing and soothing to open her mouth and to swallow the finely chopped food. She needed a great deal of time to chew the food and to swallow it. Her mother had to fully support the child's body as she fed her. Claimant coughed a few times but was able to clear her airway. She ate about one-third of her meal.
- (C) The nurse consultant found that the meal was an "extremely long, tedious and stressful experience" for claimant, her family, and caregivers. The nurse consultant expressed concern that claimant was not eating enough to meet her nutritional and health needs, was at risk of aspiration from oral feeding and dysphagia, and suffered from severe constipation. The nurse consultant recommended, in part, a behavioral assessment and follow-up with her physicians. The nurse consultant found that claimant's total care needs were "primarily supportive and custodial" and could be provided by unlicensed personnel who were specifically trained in supportive therapeutic interventions. However, the nurse consultant found that, because she choked, gagged, coughed, bit her lips and tongue and was resistant during meals and due to the risk of aspiration, claimant should be fed orally but only by family members and not by caregivers. The nurse consultant also recommended support group therapy for the family due to the stressful home environment caused by claimant's behaviors, which included crying and irritability.
- (D) On January 3, 2006, nurse consultant Zalenski raised with the mother the issue whether claimant should be fed by a G-tube. The mother was adamantly opposed to G-tube feeding for her daughter. The mother wanted her daughter to continue experiencing and enjoying the process of eating and felt that she could be fed safely by oral means despite the risk of aspiration. The mother noted that claimant has never had an incident of aspiration.
- 20. On February 1, 2006, the Service Agency wrote a "decision letter" to claimant's mother, informing her that the regional center had carefully reviewed the information and reports from the nursing consultant, OT-feeding specialist, and behavior analyst, and medical consultant. The Service Agency informed the mother that the regional center had decided to withdraw its proposal to reduce respite caregiver service from 12 hours per day to 24 hours per month. The Service Agency also advised that it was willing to withdraw its proposal to restrict oral feeding to

claimant by LVNs and to allow her two most experienced caregivers, including Vivian Mendez, to continue to orally feeding her as long as the mother signed a written agreement releasing the regional center and Cambrian HomeCare from liability from any consequence of oral feeding by the caregivers. The Service Agency also offered to provide claimant with a feeding therapy consultation and behavior intervention services.

- 21. (A) On February 5, 2006, claimant's mother told the service coordinator that her daughter needs "skilled, therapeutic care" and not nursing or respite care. The mother replied that LVN care is not appropriate for claimant.
- (B) On February 7, 2006, the mother reiterated that claimant does not need LVN care and she was not requesting such care. The mother again stated that her daughter needed "supportive therapeutic care by someone trained in therapeutic handling, positioning, massage, exercises, feeding, etc." She requested that the regional center provide 12 hours per day of appropriate care for claimant, including oral feeding, as well as feeding and behavioral therapies to help her eat and reduce biting of her lips and irritability. The mother added that the regional center's decision to prohibit oral feeding of her daughter was wrong and causing unnecessary stress.
- 22. On March 26, 2006, the Service Agency scheduled an interview of a LVN to care for and feed claimant. The mother and her sister appeared for the interview. The mother stated that she had hired a caregiver and did not agree that her daughter needed care or to be fed by a LVN. She was angry and upset with the regional center about its decision to impose LVN care upon her daughter or to allow non-LVN care and oral feeding only if she signed a written agreement releasing the regional center and Cambrian from liability from oral feedings of her daughter.
- 23. About three months later, on June 14, 2006, the Service Agency acknowledged to claimant's mother that she was "frustrated because [the regional center's] position on some issues [had] changed over time" The Service Agency also acknowledged that claimant's medical providers were supportive of oral feedings for her daughter. The Service Agency stated that it would allow any current or new Cambrian caregiver to orally feed her daughter if they were properly trained and provided claimant's mother signed the waiver or release form. The Service Agency indicated that release form was required because it could not ignore the opinions of its clinical staff and claimant's physicians that there was a risk to claimant from oral feedings. The Service Agency indicated that it needed claimant's mother to indicate by signing the release form that she was aware of the risks and did not intend to hold the regional center responsible if claimant was harmed by oral feedings by any Cambrian caregivers whose services were funded by the regional center.
- 24. (A) Three months later, on June 26, 2006, regional center nurse consultant Zalenski conducted a follow-up home visit of claimant's home at the

request of the mother. The mother had reported that her daughter had regained her weight and was happy and interacting with others again. The nurse consultant noted that a behavioral and feeding assessment of claimant was conducted in or about December 2005. Beginning in February 2006, claimant received behavior intervention therapy provided by the regional center. In March 2006, claimant's neurologist had stated that his patient had never had any episode of aspiration pneumonia, choking, or any other medical complication from oral feeding and was safe to be fed orally. The neurologist indicated that claimant did not need skilled nursing care and could be fed safely by caregivers trained by the family. The nurse consultant noted that, on March 30, 2006, claimant's pediatrician stated he was in support of continued oral feedings and supportive feeding therapy. Beginning in April 2006, claimant received two hours monthly of in-home occupational therapy to address her dysphagia.

- (B) With respect to claimant's health in June 2006, nurse consultant Zalenski found that she appeared in good health. Her eating and drinking skills had improved over the prior four to five months which the mother attributed to feeding therapy and behavioral intervention. Claimant weighed 34 pounds which was six more pounds that she weighed at the last nursing assessment five months earlier in January 2006. The nurse consultant found that claimant had regained the weight that she lost in the last few months of 2005. Based on a physical examination, the nurse consultant found claimant was petite for her age but very strong. During the nurse consultant's home visit, claimant was cheerful and playful, reacted to auditory and tactile stimulation, responded to her mother and caregiver with facial expressions including smiles. In the home, the nurse consultant observed the following equipment for claimant: wheelchair, bath chair, bicycle, pro-stander, gait trainer, and positioning chair.
- (C) On June 26, 2006, the nurse consultant observed claimant in her home for three hours. Claimant was relaxed and interactive, listened and responded, and was much healthier than during her nursing assessment earlier in the year. Claimant participated in passive movement and stretching exercises, including exercises on a large plastic ball. She lowered herself to a seated position when asked to sit. She demonstrated a happy attitude even during her dinner. She was able to eat her meal of thick vegetable soup within 45 minutes and appeared to enjoy eating. Claimant demonstrated a strong cough reflex and periodically cleared her own airway. She drank a small amount of liquid after her meal.
- (D) Following her observation on June 26, 2006, nurse consultant Zalenski recommended that the in-home intervention and feeding therapy techniques employed by the mother be followed by all caregivers providing care to claimant. The nurse consultant also recommended that caregivers be trained in the behavioral intervention and feeding therapy techniques employed in the home to ensure that claimant received consistent care and support. The nurse consultant recommended

that claimant continue her consultations with her pediatrician, neurologist, gastroenterologist, and dentist.

Psychotherapy

- 25. Claimant's mother received individual psychotherapy from Dr. Lewin on the following initial dates: October 31, 2005, and November 4 and 14, 2005. The mother first saw Dr. Lewin when her daughter was unhappy and refusing to eat. The mother and the family were undergoing a great deal of stress. During her first session, Dr. Lewin suggested to the mother, in part, that she put her thoughts in writing, make a list of problems and possible solutions, try to get out of the house, and talk to someone.
- 26. On November 15, 2005, claimant's mother asked the Service Agency for reimbursement of therapy sessions with Dr. Lewin. She forwarded copies of the invoices. She had paid cash for the visits. The mother stated that Dr. Lewin had helped her and her family with difficult issues.
- 27. (A) Claimant's mother received individual psychotherapy from Dr. Lewin on the following subsequent dates: January 16, 2006; February 10, 2006; March 14, 23, and 30, 2006; and April 20 and 27, 2006.
- (B) Claimant's brother received individual psychotherapy from Dr. Lewin on November 5, 2005, and January 16, 2006.
- (C) Claimant's father received individual psychotherapy from Dr. Lewin on November 5, 2005, and May 19 and 26, 2006.
- 28. (A) On December 16, 2005, the Service Agency met with claimant's mother to discuss her request for reimbursement for the costs of psychotherapy with Dr. Lewin. The regional center indicated it would check and see if Dr. Lewin could be made an authorized vendor. The mother also signed consent forms, agreeing that the Service Agency could contact Dr. Lewin and two other medical providers about their qualifications and services.
- (B) On February 7, 2006, claimant's mother forwarded to the regional center copies of two invoices totaling \$450 for two psychotherapy sessions with Dr. Lewin. The mother inquired when the regional center was going to respond to her request for reimbursement of the costs of psychotherapy with Dr. Lewin.
- (C) On February 19, 2006, claimant's mother again requested that the Service Agency reimburse her for psychotherapy sessions with Dr. Lewin.

- (D) On March 7, 2006, the Service Agency informed claimant's mother that it had "agreed to consider funding" "family therapy visits" with Dr. Lewin inasmuch as the regional center staff understood that the family was undergoing increased stress due to claimant's ongoing care needs. The Service Agency, however, asked for information about the type of therapy provided, treatment goals, frequency of sessions, and expected duration of therapy. The Service Agency also asked why claimant's private insurance company was not covering the cost of this service.
- (E) In a letter dated April 3, 2006, Dr. Lewin stated that he was providing weekly interpersonal neurobiology therapy to claimant's mother to help her cope with stress. He indicated that the goals of treatment were to decrease the frequency, intensity, and duration of her stress. The projected end of therapy was July 1, 2006.
- (F) On May 29, 2006, claimant's mother forwarded invoices or statements from Dr. Lewin for psychotherapy sessions from October 2005 through April 2006, explanation of benefits forms issued by the family's health insurance company Blue Shield, and the letter by Dr. Lewin dated April 3, 2006.
- 29. (A) On June 7, 2006, claimant's mother received individual psychotherapy for 45 minutes from Dr. Lewin. The fee for this psychotherapy session was \$350.
- (B) Except for claimant's mother's session in June 2006, the cost of each psychotherapy session with Dr. Lewin was \$225. Claimant's family paid Dr. Lewin the sum of \$3,725.00 for psychotherapy sessions in 2005 and 2006.
- (C) Claimant's father has health insurance for the family with Blue Shield of California and submitted claims to the health insurance company for the psychotherapy sessions with Dr. Lewin. Blue Shield did not pay for any portion of the bills for psychotherapy because Dr. Lewin was not a participating provider with the health insurance company and claimant's family had not met its annual deductibles. Claimant's family was responsible for full payment of Dr. Lewin's bills for services.
- 30. (A) On June, 23, 2006, the Service Agency met with claimant's mother and agreed to contribute \$50.87 per hour towards the weekly fee charged by Dr. Lewin. The Service Agency indicated that \$50.87 was the hourly rate that it was authorized to pay by the Department of Developmental Services. The Service Agency agreed to provide the funding for three months and, if additional funding was requested, claimant had to give consent to the regional center psychologist to talk with Dr. Lewin to determine whether further treatment was needed. The Service Agency acknowledged that claimant's mother had provided sufficient information of the therapy visits, offered to begin reimbursing claimant's mother for psychotherapy

sessions with Dr. Lewin as of June 5, 2006, and requested documentation of weekly therapy visits.

- (B) In addition, the Service Agency also wrote to the mother that it "appreciate[d] [her] willingness to sign a waiver and release form so that we can move forward with allowing properly trained HRC caregivers to orally feed [claimant]." Claimant's mother did not agree with the regional center's proposal or request to sign the waiver and release.
- (C) On August 3, 2006, the Service Agency acknowledged that claimant's mother disagreed with the proposal to pay \$50.87 per hour towards the fee charged by Dr. Lewin for individual psychotherapy for three months of services. The Service Agency reiterated that this was the rate authorized by the Department of Developmental Services and provided claimant with her appeal and fair hearing rights and information.
- 31. Claimant's mother last saw Dr. Lewin for individual psychotherapy on June 7, 2006.

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Based on the foregoing findings of fact, the Administrative Law Judge makes the following determination of issues:

LEGAL CONCLUSIONS

Grounds exist under the Lanterman Developmental Disabilities Services Act to grant claimant's request for reimbursement for private or family psychotherapy, based on Findings 1-31 above.

Under the Lanterman Developmental Disabilities Services Act, the Legislature has decreed that persons with developmental disabilities have a right to treatment and rehabilitative services and supports in the least restrictive environment and provided in the natural community settings as well as the right to choose their own program planning and implementation. (Welf. & Inst. Code, § 4502.) Welfare and Institutions Code sections 4640.7 and 4646, subdivision (a), provide that the delivery of services should be done in a cost-effective manner and section 4648, subdivision (a)(2), provides that services and supports must be individually tailored to the consumer or client.

The Legislature has further declared regional centers are to provide or secure family supports that, in part, respect and support the decision making authority of the family, are flexible and creative in meeting the unique and individual needs of the families as they evolve over time, and build on family strengths and natural supports. (Welf. & Inst. Code, § 4685, subd. (b).)

In addition, Welfare and Institutions Code section 4648, subdivision (a), provides that regional centers shall secure services and supports that meet the needs of the consumer as determined in the consumer's individual program plan and may purchase services or supports for a consumer which the regional center and consumer determine will best accomplish all or any part of the consumer's program plan. When selecting a provider of a consumer's services and supports, the regional center is required to consider, in part, the provider's ability to deliver quality services or supports which can accomplish all or part of the consumer's program plan and a provider's success in achieving the objectives set forth in the individual program plan.

In the present matter, claimant has established by the preponderance of the evidence that reimbursement for private or family psychotherapy is warranted under the circumstances. Beginning in or about September 2005, claimant's family experienced a crisis that threatened to tear apart the fabric of the family. After returning from a five-week therapeutic trip to Poland with her caregiver Mendez, claimant exhibited troubling behaviors and serious eating problems at home. She did not interact with family members and did not let anyone touch her. She was irritable and resistant. She refused to eat or take her medications. Claimant lost weight. She did not want to do her exercises or play. Meals were prolonged and stressful as claimant cried and screamed. Claimant's brothers went to their bedrooms and closed their doors.

In late October 2005, claimant's mother asked for help from the Service Agency, stating that her daughter was unhappy and it was very difficult and stressful to feed her. The mother described the situation at home as an impending disaster and she feared for the safety of her family. Believing that there was an emergency in the family, the mother was compelled to see Dr. Lewin, a psychologist, for immediate intervention. In November 2005, the mother wrote that the claimant and the family were suffering and the situation was worsening. Her husband and son both saw Dr. Lewin for emergency counseling for the stressful home situation. Claimant's mother asked that the regional center reimburse the family for the psychotherapy costs. She also asked for the services of a feeding specialist and behaviorist for her daughter as suggested by her daughter's medical specialists.

With respect to the requests for services, the Service Agency responded in an appropriate manner. In or about November and/or December 2005, the regional center had claimant assessed by the occupational therapist and feeding specialist recommended by one of claimant's doctors and evaluated by a behaviorist. Claimant began receiving both feeding therapy and behavioral intervention at the end of 2005

or beginning of 2006. She received occupational therapy in April 2006 to address her dysphagia. By June 2006, claimant was eating as she had before the fall of 2005, had regained her weight, and was happy and responsive at home. The regional center nurse consultant confirmed claimant's recovery and recommended that her caregivers continue to care for claimant with training in the feeding and behavioral techniques employed over the past few months.

On the other hand, the evidence demonstrated that the Service Agency failed to provide or secure the psychological counseling and support that claimant's family needed and requested during the crisis arising from her feeding and behavioral problems in the fall of 2005. It was not established that the regional center held an individual program plan meeting at any time to answer claimant's mother request for reimbursement for the family counseling. After the mother made an emergency visit to the psychologist in late October 2005, the regional center did not suggest counseling with another provider or clearly indicate that the sessions with Dr. Lewin were not reimbursable. Instead, the regional center requested information about the psychologist and began to focus on claimant's feeding problems and weight loss, especially after her emergency room visit for dehydration, to try to change the program implemented by her mother for several years.

In December 2005, the regional center's medical consultant determined that it was not safe to feed claimant orally and recommended G-tube feeding. The regional center also took the position that claimant should be cared for and fed only by LVN's and not by Cambrian caregivers, including claimant's long-time caregivers. Due to the risk of aspiration, the nurse consultant recommended that claimant be fed orally but only by family members and not by caregivers. In addition, the regional center proposed reducing caregiver service from 12 hours daily to 24 hours monthly. Finally, in February 2006, the regional center indicated its willingness to withdraw the restriction that only LVN's feed claimant and allow oral feeding by caregivers on condition the mother sign a release or waiver of liability. The regional center did not make a decision about the mother's request for reimbursement for psychological counseling until June 2006 by which time the mother had stopped seeing Dr. Lewin.

While the regional center had good reason to be concerned about its client's health, the evidence was not clear that the cause of the claimant's health problems in late 2005 was actually oral feeding. There appeared to have been behavioral and family components as well as developmental or neurological issues related to Canavan's disease that led to her problems and refusal to eat. And her mother clearly expressed her preferences for the care of her daughter. She became very upset about the regional center's proposals and demands. She objected to insertion of a G-tube for feeding, insisting that her daughter be fed orally. She believed that her daughter did not need the higher level of care provided by LVN's and was fine with her existing level of care with the Cambrian caregivers if she received feeding therapy and behavior intervention. She did not want to sign any release or waiver. The Service Agency acknowledged that its changes of positions

caused the mother to be frustrated. In many ways then, the regional center's decisions and proposals with respect to feeding and the level of care may be viewed as having worsened the fragile psychological balance of the mother and the family. She continued to see Dr. Lewin in 2006 for counseling. And as it turned out, the mother was correct. After several months of feeding therapy and behavioral intervention and continued oral feeding, claimant improved and regained her weight and happiness. Claimant did not suffer any ill consequences from her oral feedings by her parents and caregivers.

As provided under the Lanterman Act, claimant's mother has the right to choose her daughter's own programming and to have her receive services and supports that are individually tailored to her needs. The regional center is required to respect the decisions of the family and to be flexible and creative in meeting the unique needs of the client and family. When the family was undergoing a singular crisis due to claimant's behaviors and feeding problems, the Service Agency could have been more responsive and flexible after taking into consideration the unique circumstances of claimant's disabilities and needs and the planning and efforts of her mother in trying to give her daughter a semblance of a normal childhood. The individual psychotherapy provided to the mother and family was akin to therapy for the family in order to deal with the stress of dealing with claimant's myriad problems and behaviors at home.

The offer of the Service Agency to begin reimbursing claimant's family for therapy sessions with Dr. Lewin beginning on June 5, 2006, at the \$50.87 hourly rate set by the rules or regulations of the Department of Developmental Services was untimely and inadequate. By that juncture, the family crisis had already been resolved and claimant was back to her normal routine. And common sense and experience would indicate that the proffered authorized rate is much less than the normal rate charged by practicing psychologists in the community. As a matter of equity and fairness, claimant's family shall be reimbursed for the 16 hour-long sessions with Dr. Lewin at the hourly rate of \$150.

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Wherefore, the Administrative Law Judge makes the following Order:

ORDER

The appeal or request of claimant Hannah G. that the Harbor Regional Center reimburse the costs of psychotherapy will be granted. Harbor Regional Center shall reimburse claimant in the sum of \$2,400.00 for psychotherapy sessions provided by Melvyn M. Lewin, Ph.D., in years 2005 and 2006. Payment shall be made within 30 days of the date of this Decision.

Dated:

Vincent Nafarrete Administrative Law Judge Office of Administrative Hearings

NOTICE

This is the final administrative decision pursuant to Welfare and Institutions Code section 4712.5. Both parties are bound by this decision and either party may appeal this decision to a court of competent jurisdiction within ninety (90) days.